# An Evaluation of NIDCR Oral Health Disparities Research 2001-2006

National Institute of Dental and Craniofacial Research
Office of Science Policy and Analysis

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# An Evaluation of NIDCR Oral Health Disparities Research, 2001-2006

## Chapter One: Introduction

During the late twentieth century, a steady decline in dental caries and tooth loss helped to improve the quality of life for many people in the United States. Unfortunately, these benefits did not reach all Americans. Many oral and dental conditions are still more common, more severe, and more often untreated in certain population groups—including racial and ethnic minorities, low-income families, inner city and rural residents, persons with disabilities, and others.

Due to preventive measures such as community water fluoridation and dental sealants, the overall rates of dental caries (tooth decay) have declined significantly. However, dental caries is still the most common chronic infectious disease of childhood, and tooth loss in adulthood is a persistent problem. Severe early childhood caries, a severe form of the disease in primary teeth, can cause considerable pain and forces very young children to undergo tooth extraction, sometimes under general anesthesia. Untreated caries can be painful, disfiguring, and even fatal if the infection spreads to other parts of the body.

Another major cause of tooth loss in adults is periodontal disease. Like caries, periodontal disease is more often found in African-Americans as compared with whites, even after adjusting for a number of predisposing factors. Periodontal disease is especially common among low-income families, who have fewer resources to obtain the care needed to save their teeth.[1]

Oral, head and neck cancers are the most deadly of all oral diseases, and unfortunately there are also significant disparities associated with these conditions. Oral cancer is the seventh most common cancer in the US male population and takes a disproportionate toll on minorities; it now ranks fourth among the common cancers of African American men. African-American males are 1.3 times more likely to get oral cancer compared with white males. Mortality rates for oral cavity cancer for African-American males are twice as high as for white males. Similarly, the 5-year survival rate for oral cavity cancer in African-Americans is markedly lower than for Whites, regardless of the stage at diagnosis.[2]

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[1] See L.N. Borrell et al, "The role of individual and neighborhood social factors on periodontitis: the third National Health and Nutrition Examination Survey", Journal of Periodontology, 2006, 444-453.

[2] American Cancer Society. Cancer Facts and Figures for African-Americans 2003-2004. Atlanta (GA), American Cancer Society; 2003.

Health disparities issues are complicated to address because they reflect the complex nature of health and illness. It is difficult to explain why some people are healthy and others are not -- multiple, interdependent factors are at work, and the way these factors combine to determine health is often not well understood. Unique biological mechanisms can blend with environmental cues to create the conditions for disease. These interactions may be manifested in the body's response to stress, for example. Individuals may inherit a predisposition to specific diseases, or they may engage in behavior that lowers their likelihood of exposure to harmful factors. In addition, the environment, especially the communities and neighborhoods where people live, can contain unhealthy or protective features. Furthermore, the type of health care available and accessed can play an important role in widening or mitigating disparities. Many low-income families lack dental insurance and have limited funds to pay for dental care, and may also lack transportation to visit a dental clinic. As a result, postponed preventive care and treatment can lead to higher levels of disease. Because studies show that disparities persist even after adjusting for differences in availability of care, it is clear that access alone will not eliminate oral health disparities. It is equally clear that improved access can help mitigate the impact of oral health disparities.

As an important part of its overall mission of improving oral health in the United States, the National Institute of Dental and Craniofacial Research (NIDCR) supports research to address minority health and health disparities. NIDCR's efforts to address health disparities were expanded in 2001, with the release of the Institute's "Strategic Plan to Eliminate Craniofacial, Oral, and Dental Health Disparities". The plan's goals centered around three key areas -- research, research capacity, and information dissemination. Strategies identified in the plan included the establishment of Centers for Research to Reduce Oral Health Disparities (funded in 2001), activities to enhance research capacity, and outreach efforts.

## Scope, Objectives, and Methodology

To assess the implementation of this strategic plan and to assist with future planning activities, staff from NIDCR's Office of Science Policy and Analysis have designed a prospective evaluation of NIDCR's portfolio in oral health disparities research from 2000 to 2006. The portfolio comprises over 100 grants and projects annually. These projects cover a wide variety of research areas, including caries, oral cancer, periodontal disease, craniofacial anomalies, and others. A number of different population groups are represented, including African Americans, Puerto Ricans, Mexican Americans, rural residents, and low-income families.

An important part of this portfolio is the Centers for Research to Reduce Oral Health Disparities. The Centers, which were first funded in 2001, are located at Boston University; New York University; University of California at San Francisco; University of Michigan; and the University of Washington. Several key aspects of supporting health disparities research, including training, are concentrated in these centers. For this reason, the evaluation pays special attention to the activities of the health disparities centers.

The objectives of this evaluation are to:

1. review the characteristics of NIDCR's health disparities research from 2000-2006, and to assess how these characteristics correspond to the objectives of NIDCR's health disparities plan;
2. identify the publications, interventions, and outcomes that have resulted from NIDCR's 2000-2006 health disparities research;
3. determine whether additional research capacity has resulted from NIDCR's 2000-2006 activities in the area of oral health disparities;
4. determine if the research support mechanism has affected the results of NIDCR's research in oral health disparities, and if so, how.

A variety of methods to obtain information pertaining to the objectives of the overall evaluation were employed. First, a portfolio analysis was conducted using the Institute's scientific coding system (which is known as SCORE). SCORE includes detailed information on all of NIDCR's funded grants, enabling us to analyze the health disparities portfolio by disease or condition, population groups, and other areas. Second, the literature was analyzed to identify a baseline for health disparities publications. We obtained all publications from center PIs, core PIs, and project PIs associated with NIDCR's health disparities centers, from 1990 to the present. The literature was also searched for all oral or dental health disparities publications from 2001 to 2006. For each article, we recorded and analyzed information on all authors and their affiliations, disease area, subject populations, publication type, sample type, funding sources, and the purpose or objective of the research.

Third, because of the unique role the research centers play in NIDCR's health disparities portfolio, we conducted case studies of each of the five NIDCR-funded Centers for Research to Reduce Oral Health Disparities. We reviewed grant applications, progress reports, pilot project applications, minutes of advisory committee meetings, study protocols, and other documents related to each center. In the fall and winter of 2003-2004, and again in the fall and winter of 2006-2007, we visited each of the five centers. During these visits interviews were held with the center PI and Co-Director, all subproject PIs, all core PIs, all PIs of center-affiliated projects, at least one PI from a pilot project, representatives from the center's major educational and community partners,

and other selected individuals associated with the center. Information from each of these sources is included in this report. However, data specific to individual centers, projects, or grants are excluded. For each center, we also reviewed the center web site to assess the center's visibility on the web, the quantity of information provided on the web site, whether the web site was kept up to date, and ease of navigation and accessibility. Finally, we reviewed the current and past NIH grant applications for each center researcher, to identify spinoff projects and help assess research productivity.

Several significant factors limit the analysis and interpretation of these data. First, data from interviews with the individuals associated with the disparities research centers are self-reported. Furthermore, some of the results of both the literature analysis and the center case studies are based on a relatively small number of observations. Most important, many of the grants and research projects included in this evaluation study have been in place for only a few years. A number of these studies are ongoing, or were completed relatively recently. The full results of this research are not yet be available. For these reasons, findings from this evaluation study should be considered preliminary.

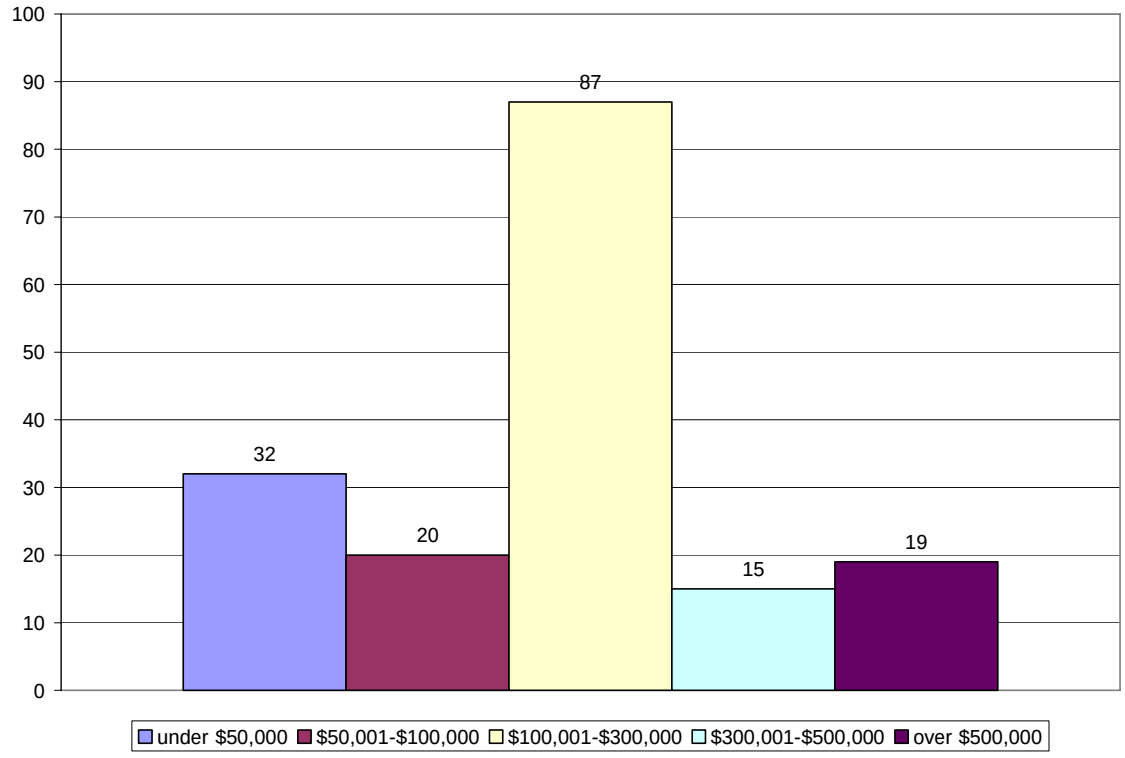
## Chapter Two: NIDCR's Portfolio in Oral Health Disparities

### NIDCR's Overall Health Disparities Portfolio

In fiscal year 2006, NIDCR identified $45.6 million in spending related to oral health disparities research.[3] A total of 173 research grants and projects accounted for this total. The projects ranged from large-scale clinical trials to small grants for secondary data analysis.

As shown in Figure 2.1, the health disparities grants in this portfolio ranged widely in size, from around $20,000 to over $2 million. The average award amounted to $245,071. About 31 percent of the awards amounted to less than $100,000 annually, and 21.4 percent amounted to over $300,000 annually.

Figure 2.1: Number of NIDCR Health Disparities Grants and Projects Active in 2006, by Funding




The size of the grant awards in oral health disparities was consistent with the distribution of these grants by research mechanism. As illustrated in Table

[3] In 2003, NIH changed the method for identifying health disparities research at all NIH institutes. For this reason, the reported figures from before and after 2003 are not comparable.

2.2, the NIDCR health disparities portfolio included a smaller proportion of R01 grants, and a higher proportion of U54 centers, compared with the overall NIDCR extramural portfolio.

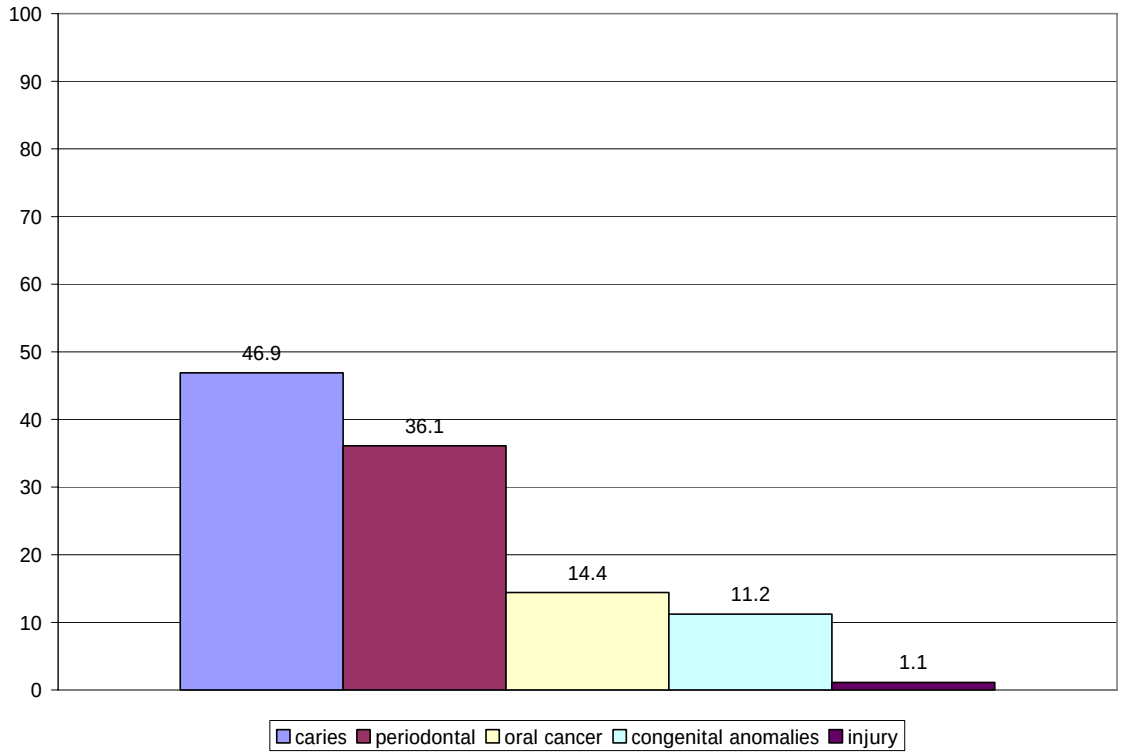
Table 2.2: NIDCR Health Disparities Funding and All Extramural Funding by Activity Code, 2006

| Activity code | Percent of health disparities funding | Percent of all extramural funding |
|---|---|---|
| R01 | 42.2 | 54.5 |
| R03 | 2.5 | 1.6 |
| R21 | 2.9 | 3.7 |
| R37 | 1.0 | 1.4 |
| U54 | 27.1 | 3.9 |

Note: Percentages will add up to less than 100 because this table does not include all activity code mechanisms.

The portfolio of health disparities grants is essential to fulfilling the goals of NIDCR's health disparities strategic plan. This plan identified several areas to be targeted in the effort to reduce disparities--oral infections (dental caries and periodontal diseases); oral, head and neck cancers; congenital anomalies; and oral injuries. Although these areas were all included in the plan, they were not equally well represented in the health disparities portfolio. As seen in Figure 2.3, the health disparities portfolio emphasized dental caries and periodontal diseases, with limited coverage of the other disease areas included in the health disparities strategic plan.

Figure 2.3: Percent of Funding in NIDCR's 2006 Health Disparities Portfolio, by Condition




Note: percentages may add to more than 100 because the categories are not exclusive.

## Centers for Research to Reduce Oral Health Disparities

The five Centers for Research to Reduce Oral Health Disparities constituted a major portion of NIDCR's health disparities portfolio, accounting for about 17 percent of the research grants and projects and 27 percent of expenditures. These centers are important not only because of their size, but because they have a unique role in fulfilling the health disparities plan. In addition to conducting oral health disparities research, the centers are intended to increase the overall capacity to conduct this type of research in the future. For example, the centers have been expected to serve as a national resource for other researchers. In addition, it was anticipated that the relationships developed between the centers and their local communities would result in increased capacity to conduct community-based research in oral health disparities.

The five centers are located across the country—in Boston; New York City and Puerto Rico; Detroit Michigan; San Francisco; and Seattle. The centers differ in their focus on specific conditions and populations. They have also

taken differing approaches to developing research capacity. Each center is described below.

**Boston University Center:** The Boston University Center for Research to Reduce Oral Health Disparities is focused on the impact of caries in children and adolescents. The center's projects are targeted toward multiple racial and ethnic groups, especially Hispanic and African American populations and low-income families in Boston and surrounding area. For example, one project team is developing a survey instrument to measure oral health-related quality of life in children and adolescents. The instruments are available in English and Spanish and also include clinical, demographic and psychosocial measures. Another project is concerned with educating pediatricians in preventing Early Childhood Caries in children from low-income families. Another project being conducted in Washington, D.C., Columbus and Cincinnati, Ohio at Boston University is designed to explore the relationship between Early Childhood Caries and growth and development. Finally, one research team at the Boston University center is working on identifying differences in oral microbial pathogens among children with and without caries, as well as variations among different racial groups of children with caries.

**New York University Center:** Researchers at the New York University (NYU) center have focused their attention on early detection and prevention of oral cancer in African-American and Hispanic men. This center's projects are located in several different areas, including Puerto Rico and New York City. One epidemiology project supported by the NYU center is focused on risk factors for oral epithelial dysplasia in Puerto Rican males, especially the links with smoking and alcohol and potential genetic polymorphisms. Another team of researchers is testing new and established methods and technologies for early detection of oral cancer. In another project, investigators are using a survey to measure the willingness of African Americans, Puerto Ricans and Hispanics to participate in cancer screening exams and in clinical trials. The NYU Center has also formed a partnership with the University of Puerto Rico (UPR), to help UPR build additional research capacity in oral health and oral health disparities.

**University of California at San Francisco (UCSF) Center:** Research projects at the UCSF center are largely concentrated on Early Childhood Caries. Center investigators are studying multiple population groups in the San Francisco, Mendota, and San Ysidro areas of California, hoping to improve understanding of how to prevent oral health disparities. For example, in one project researchers are conducting a randomized clinical trial based in San Ysidro, California. This study is assessing the impact of

a combination intervention (chlorhexidine and fluoride varnish) in preventing Early Childhood Caries in mothers and infants in a Hispanic community. In addition, UCSF researchers are using ethnographic and qualitative methods to explore the factors relating to dental utilization and factors that determine acceptance of different interventions in a Hispanic population. The UCSF center also includes projects in traditional and genetic oral epidemiology to inform the development of new conceptual models and interventions.

**University of Michigan at Ann Arbor Center, or Detroit Dental Health Project**: The University of Michigan Center for Research to Reduce Oral Health Disparities is focused on preventing and reducing caries in a low-income, African-American population. The center has selected a representative random sample of African Americans in the poorest 39 census tracts in the city of Detroit. These families are interviewed and included in several studies. One research team is investigating the social characteristics of parents, families, and environmental characteristics of neighborhoods that are associated with disparities in oral health and disease, while another group is exploring the relationships between caries and dietary factors and lead levels. Another center project involves developing a tailored educational intervention to prevent caries in the community. Finally, the center is also assessing the impact on access to dental care of a change in the payment system for the state Medicaid program.

**University of Washington Center**: The University of Washington Center for Research to Reduce Oral Health Disparities includes research on preventive measures for children and their caretakers in disadvantaged families who suffer from poor oral health. This center's projects cover a variety of racial and ethnic groups, including Hispanics, Alaska Natives, Asian, rural-dwelling, Caucasians, African immigrants. This center includes one project designed to study the effect of early intervention of orthodontic care for children of low-income families under Medicaid. In addition, a team of center researchers is investigating the effects of xylitol gum on the level of streptococcus mutans (caries-causing bacteria) in young adults. Other projects include testing a web-based computer intervention to reduce dental fear, developing an information resource for dentists on cultural issues, and conducting a basic research project on the role that beta defensins play in dental caries development. The University of Washington Center has also formed a partnership with Heritage College, an undergraduate college that serves a large Native American

and Hispanic population. This partnership is designed to help Heritage students and faculty gain research experience.

Preliminary Results of NIDCR Oral Health Disparities Centers--Grants and Applications

As of May 1, 2007, center researchers have submitted 164 additional research applications to the NIH. Of these, 78 applications were directly related to center applications and thus could be classified as spin-off applications. Eighteen (18) of these applications were funded as of May 1, 2007, and a number of others were pending. More information on subsequent grant applications from center researchers is provided in Table 2.4.

Table 2.4: Subsequent NIH Grants and Applications by Center Investigators, January 2002--May 2007 (updated May 2007)

| | Centers | | | | | |
|---|---|---|---|---|---|---|
| **Measure** | **BU** | **UCSF** | **UM** | **UW** | **NYU** | **Total** |
| Applications per center researcher | 2.9 | 1.5 | 2.7 | 2.8 | 2.3 | 2.5 |
| Percent of applications funded[4] | 23.1 | 33.3 | 14.3 | 25.0 | 23.1 | 24.1 |
| Percent of applications related to oral health | 81.4 | 71.4 | 57.6 | 87.1 | 100.0 | 81.8 |
| Percent of applications related to health disparities | 55.8 | 57.1 | 36.4 | 54.3 | 42.9 | 52.0 |
| Percent of applications related to projects (including pilots) at center | 41.9 | 52.4 | 9.1 | 51.4 | 39.3 | 47.5 |
| Percent of applications involving more than one center colleague | 69.8 | 52.4 | 42.4 | 51.4 | 64.3 | 56.3 |

[4] This excludes applications withdrawn for amendment and applications that are pending as of May 1, 2007.

## Chapter Three: The Research Literature on Oral Health Disparities--Characteristics and Trends

The literature on oral health disparities cuts across a wide variety of areas, including conditions from caries to oral cancer. In order to assess the impact of NIDCR's efforts, it is necessary to place the research literature supported by NIDCR in the context of the overall research literature in oral health disparities. This context is especially important for evaluation of efforts to increase research capacity in the area of oral health disparities.

### Methodology

To identify the literature, a PubMed search was conducted annually, covering the years 2001, 2002, 2003, 2004, and 2005. The search strategy included two sets of terms--(1) terms related to oral and dental health, such as dental, periodontal, caries, etc.; and (2) terms related to population groups, such as ethnicity, African American, black, names of Native American tribes, etc. All PubMed fields were included in the search. To be returned in the initial search results, the article must have included one or more terms from the first group and one or more terms from the second group. A list of search terms used in this analysis is attached in Appendix B.

Conceptually, we defined health disparities research to include all research where the specific aims of the research project are such that the results could make a contribution to better understanding and/or addressing oral health disparities. This included studies that involve comparisons among different population groups, and it also included studies that specifically target disparity groups. Research that involved disparity groups, but where those groups were not specifically targeted, was not included. In addition, studies that involved entirely non-U.S. populations were excluded.

For each article included in the analysis, we recorded a wide range of information in addition to the usual bibliographic citation information. The affiliations of the authors were recorded in their entirety, and the affiliations were classified by organization type--dental school, medical school, school of public health, nursing school, private practice, industry, government agency, nonprofit, other university department, and other.

The disease or condition, if any, was identified for each article. For example, we recorded whether the disease or condition was caries, periodontal disease, oral cancers, craniofacial anomalies, oral or facial clefts, malocculsion, or other oral condition. We also recorded systemic conditions addressed by the research, such as diabetes or heart disease.

We recorded whether the article included human subjects, and if so we identified the specific population group included in each article. For example, we indicated whether the research subjects were identified as white, black or African American, Asian, Hispanic or Latino, Native American, disability, low-income, occupation, education, or age. If specific subgroups were identified (such as Puerto Rican or Mexican American Hispanics), these were also identified.

Each article was classified by publication type--original research, review, editorial or commentary, meta analysis, case report, and other. Clinical trials and articles that included the development of new research methods were also identified separately. We also characterized the sample of subjects used in each study--for example, convenience samples, nationally representative samples, samples representative in a particular group or community, and longitudinal samples. For those publications that made comparisons across subject groups, we distinguished between research that made direct comparisons across subject groups and research that made indirect comparisons (for example, comparing a prevalence estimate in a sample group with previously published national data).

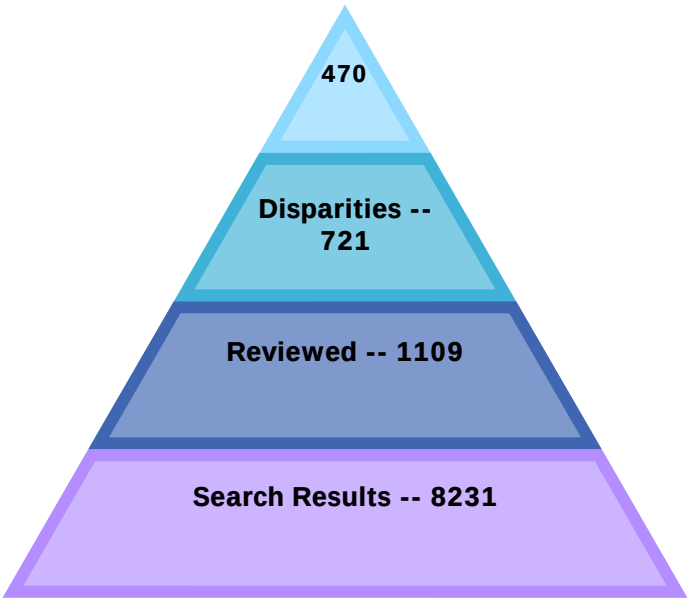
Each article was also classified by its specific aims. Publications were cataloged using 2 axes: comparison type and research type. The comparison type referred to whether the research made comparisons across population groups or targeted a specific disparity group. The research type referred to the aims and objectives of the research. For example, codes were applied for articles dealing with new prevention methods, new treatment methods, testing the effect of existing prevention methods, developing prevalence estimates, measuring morbidity, and determining utilization. A complete list of classifications is provided in Appendix C.

Furthermore, all funding sources credited in the publications were identified, by organization, grant number (if provided) and type of organization (industry, state or local government, federal government, nonprofit foundation, dental association, etc.). In addition, all outcome measures from the study were recorded. These included both clinical measures, such as DMF or ICDAS caries criteria, as well as self-reported measures, utilization, and others.

## Oral Health Disparities Literature is Small, but Growing

As Figure 3.1 shows, the literature search described above yielded a very large number of articles (8,231 in all). However, the overwhelming majority of these publications were unrelated to oral health disparities. For example, because the word "oral" was included in the search terms, the results included a large number of articles on oral contraception.[5] From the search results, 1,109 articles were reviewed in their entirety by a single abstractor to determine whether they should be included in the oral health disparities literature. Of these, 721 met the conceptual definition of oral health disparities research described above. When reviews, editorials, and commentaries were excluded, 64 percent, or 470 articles in total, remained. These 470 articles comprised the original research literature in oral health disparities in the 2001-2005 period.

Figure 3.1: Oral Health Disparities Literature Search Results, 2001-2005



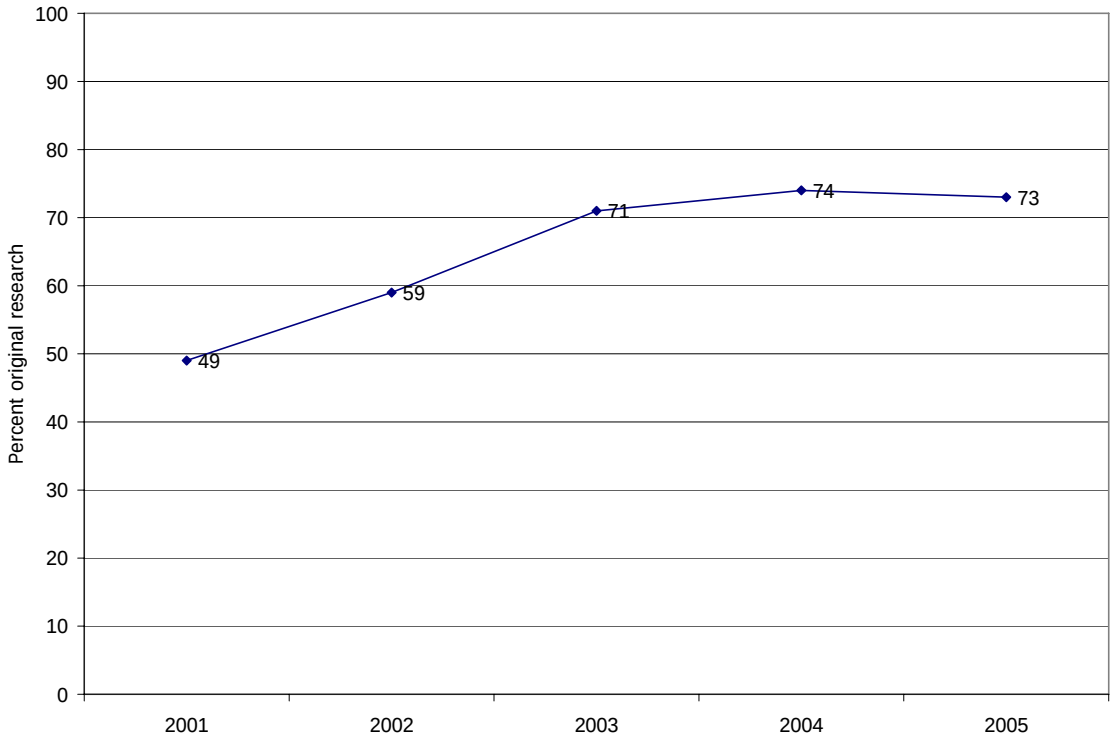

[5] Later we tested the effect of eliminating some of these terms that resulted in a large number of false positives. Unfortunately, an unacceptable number of relevant articles were excluded by the revised search, so the original strategy was retained.

The number of original research publications in oral health disparities grew over the period 2001-2005. As Figure 3.2 shows, the number of original research articles increased from well under 100 articles in 2001 to 116 articles in 2005. The total number of articles generally grew as well, although at a slower pace because the percent of publications from original research grew during this period.

Figure 3.2: Oral Health Disparities Literature by Year, 2001-2005

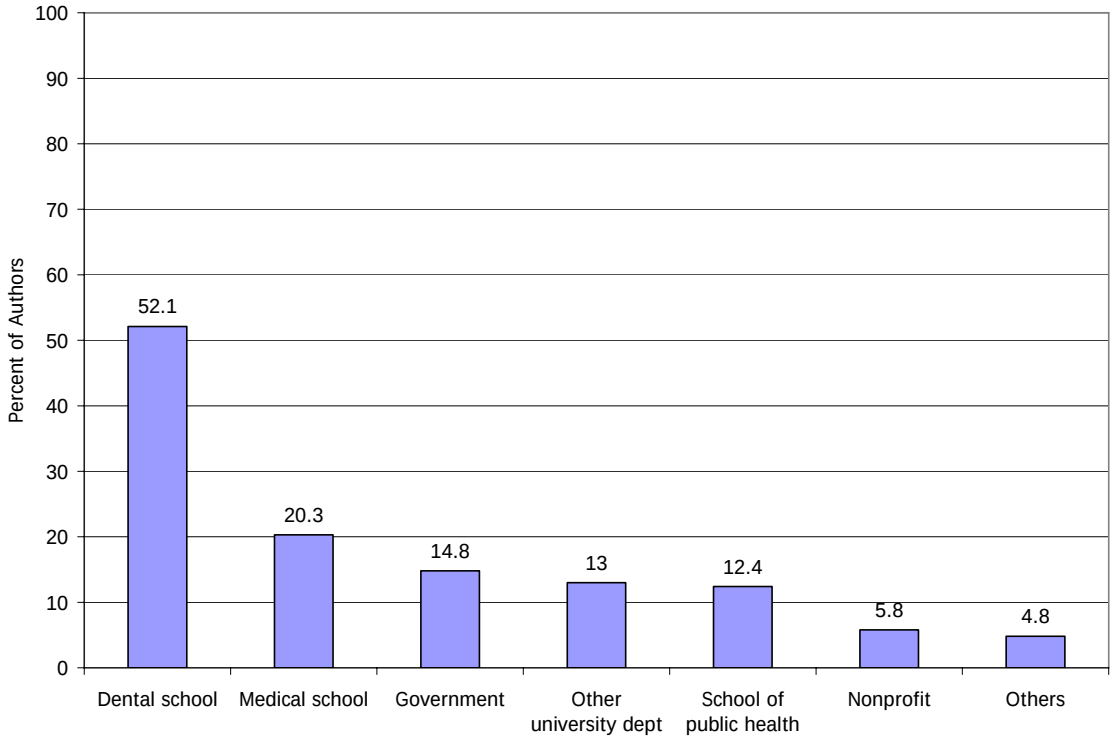
The percent as well as the number of publications that represented original research increased over this time period. In 2001, about half of the published literature was original research. Only a few years later, almost three quarters of the health disparities literature was original research. (See Figure 3.3).

Figure 3.3: Percent of Original Research in the Oral Health Disparities Literature by Year, 2001-2005



A slight majority of the researchers who published in this area were affiliated with dental schools, but other affiliations were also common. As Figure 3.4 shows, the original research literature on oral health disparities drew contributors not only from dental schools, but also from medical schools, government agencies, other university departments, and schools of public health.

Figure 3.4: Oral Health Disparities Researchers by Affiliation type, 2001-2005




Note: percentages may add to more than 100 because the categories are not exclusive.

The journals that published original research in oral health disparities reflected the diversity in the authors ranks. Of the most common journals publishing these articles, most but not all were dental journals. Several journals that specialized in health disparities research also published articles on oral health disparities. The most common journals in the field are listed in Table 3.5. Dental journals are shows in blue and non-dental journals in green.

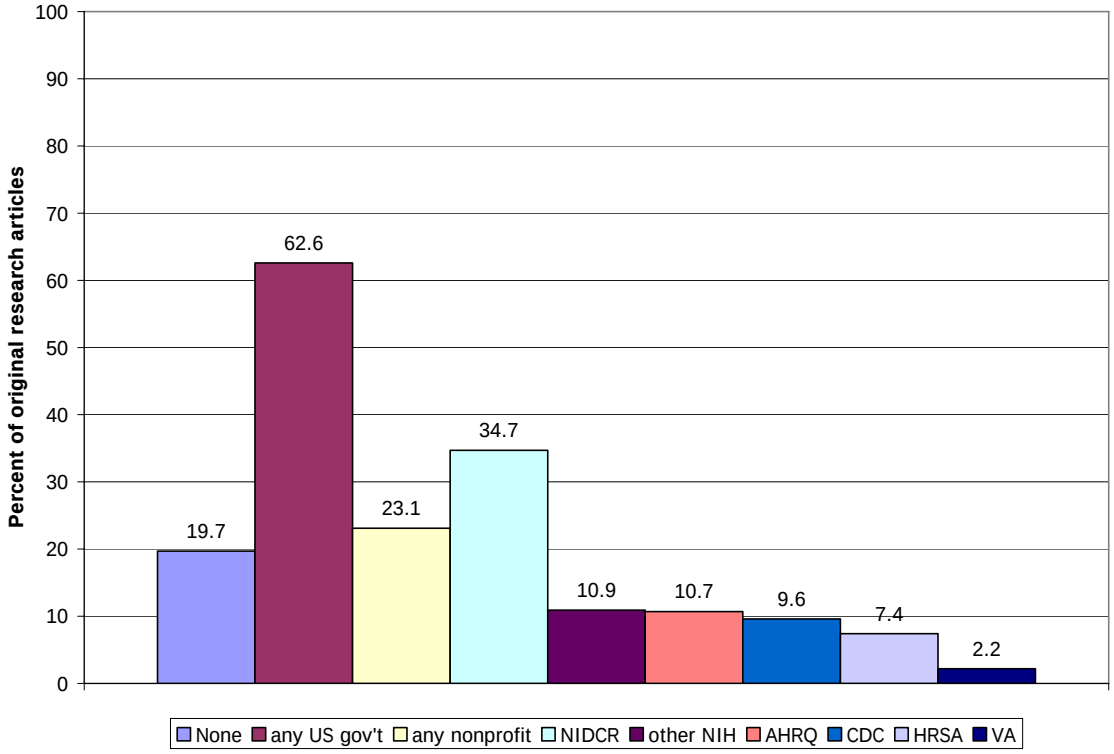
Table 3.5: Journals Publishing Oral Health Disparities Research

| Rank | Journal Title |
|---|---|
| 1. | Journal of the American Dental Association |
| 2. | Journal of Public Health Dentistry |
| 3. | Pediatric Dentistry |
| 4. | American Journal of Public Health |
| 5. | Community Dentistry and Oral Epidemiology |
| 6. | Journal of Dentistry for Children |
| 7. | Journal of Dental Research |
| 7. | Morbidity and Mortality Weekly Report |
| 7. | Pediatrics |
| 8. | Community Dental Health |
| 9. | Special Care in Dentistry |
| 9. | Health Services Research |
| 10. | Ethnicity and Disease |
| 10. | Journal of Health Care for the Poor and Underserved |

## NIDCR is a Key Funding Source for Oral Health Disparities Research

About 80 percent of the original research publications in oral health disparities credited some external funding source. Agencies of the U.S. federal government funded the majority of this research, and the most common agency in this group was NIDCR. As Figure 3.6 shows, the most common single funding source for oral health disparities research was NIDCR.

Figure 3.6: Funding Sources for Oral Health Disparities Research, by percent of credited publications, 2001-2005

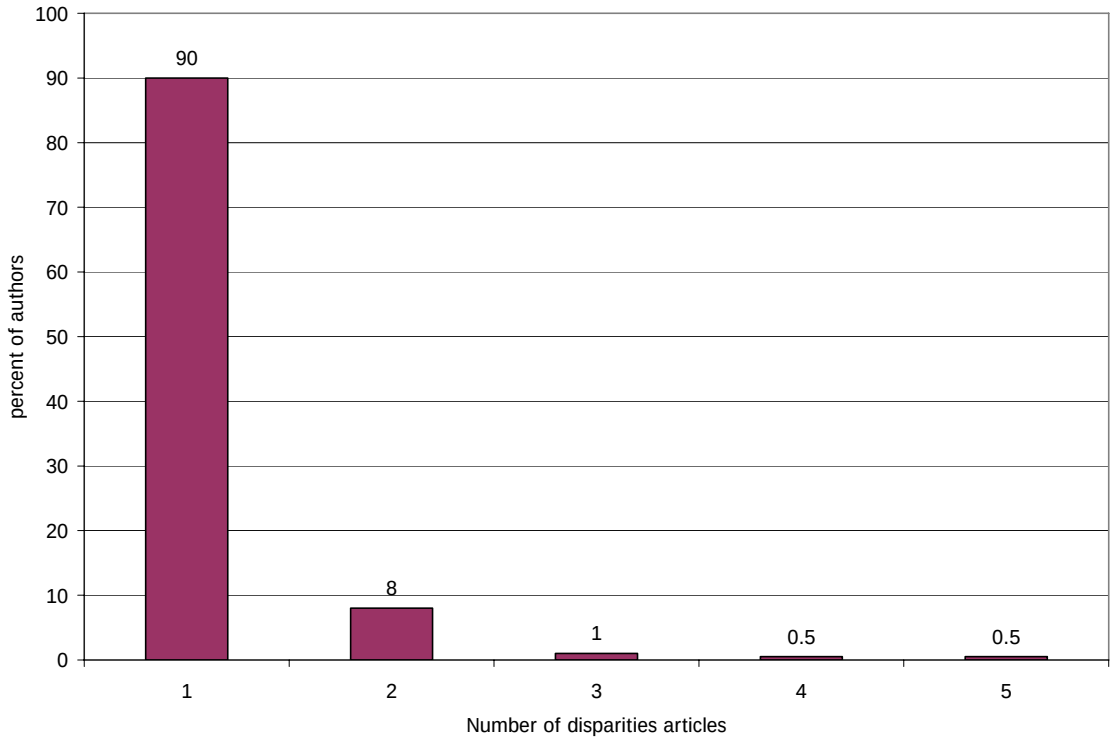



Note: percentages may add to more than 100 because the categories are not exclusive.

## Researchers Dabble, Rather than Specialize, in Oral Health Disparities

Over the 5 year period we reviewed, over 800 authors were represented in the original research literature on oral health disparities. However, 90 percent of these researchers published only one article over the five year period, and only 2 percent of the researchers published more than two articles. (See Figure 3.7). Most of these researchers were in fact publishing articles, but in other research fields. We were able to verify total publications in the 2001-2005 period for about 80 percent of the authors we identified in the oral health disparities literature.[6] About 79 percent of these health disparities authors published 3 or more articles in these 5 years. However, only a very small portion of the research workforce concentrated their efforts in the area of oral health disparities. Of the authors that published 3 or more articles, only 8 percent had 25 percent or more of their publications in the area of oral health disparities. Only 1 percent had 50 percent or more of their publications in the area of oral health disparities.

Figure 3.7: Number of Oral Health Disparities Articles by Percent of Authors, 2001-2005




[6] The remaining authors had common names and missing affiliation information, so their publication records could not be determined.

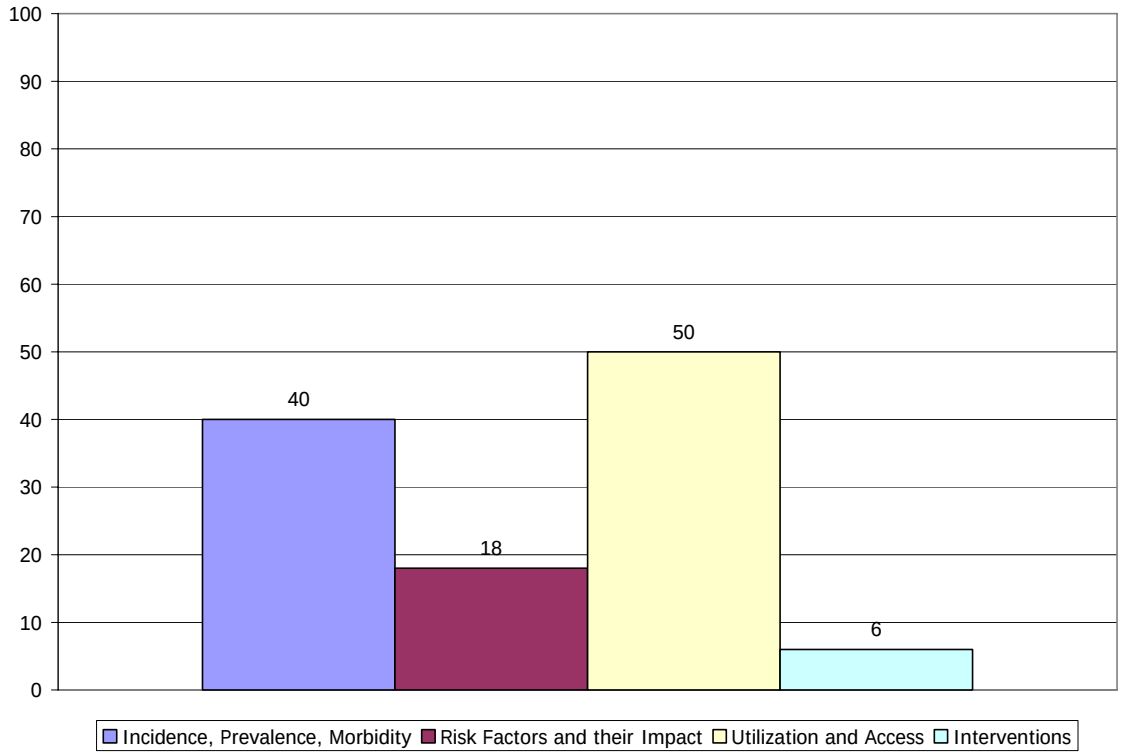
Even the scientists who became part of the Centers for Research to Reduce Oral Health Disparities have had limited prior experience with this type of research. During the baseline period of 1997-2003, only 15 percent of center researchers' original research articles related to oral health disparities. Furthermore, only two of the center researchers had published more than 50 percent of their articles in the area of oral health disparities, and one of these was relatively new. Subsequent publications and grant applications showed some growing emphasis on disparities, although not a dramatic increase. (see chapter 6.)

## Oral Health Disparities Research Has Emphasized Health Services Research and Epidemiology

The research literature in oral health disparities was overwhelmingly concentrated in the areas of epidemiology and health services research. As shown in Figure 3.8, half of the articles addressed dental utilization and/or access to care, and 40 percent related to incidence, prevalence, and/or morbidity of oral conditions.[7] By contrast, very few publications dealt with interventions to prevent and treat oral disease. Only 6 percent of the publications dealing with disparities involved interventions.

[7] Percentages will add to more than 100 because categories are not mutually exclusive.

Figure 3.8: Percent of Articles with Certain Research Objectives, Oral Health Disparities Research, 2001-2005




Note: percentages may add to more than 100 because the categories are not exclusive.

Many of the published articles in the area of oral health disparities dealt with oral health in a very general sense, rather than focusing on a specific disease or condition. As Table 3.9 shows, only 59 percent of disparities articles addressed any specific condition. The remaining publications dealt with cross-cutting issues--most commonly the utilization of dental care. The most common specific condition addressed in the literature was caries, which was addressed in 30 percent of the publications. Despite its severity, oral cancer accounted for only about 9 percent of the literature on oral health disparities.

Table 3.9: Conditions Addressed in the Oral Health Disparities Literature

| Disease or condition | Percent of 2001-2005 publications |
|---|---|
| **Any** specific condition | 58.8 |
| Caries | 30.3 |
| Periodontal diseases | 15.3 |
| Oral cancer | 8.5 |
| Tooth loss | 4.6 |
| Oral manifestations of AIDS/HIV | 3.0 |
| Craniofacial anomalies | 2.5 |
| Malocclusion | 2.5 |
| Oral injury | 1.4 |
| Others | 1.4 |

Note: percentages may add to more than 100 because the categories are not exclusive.

The outcome measures used in the literature reflected this emphasis on epidemiological and health services research. Table 3.10 shows the percent of publications using individual types of outcome measures. No one type of measure dominated the field, but utilization and access to care measures were very common.

Table 3.10: Outcome Measures Used in Oral Health Disparities Publications, 2001-2005

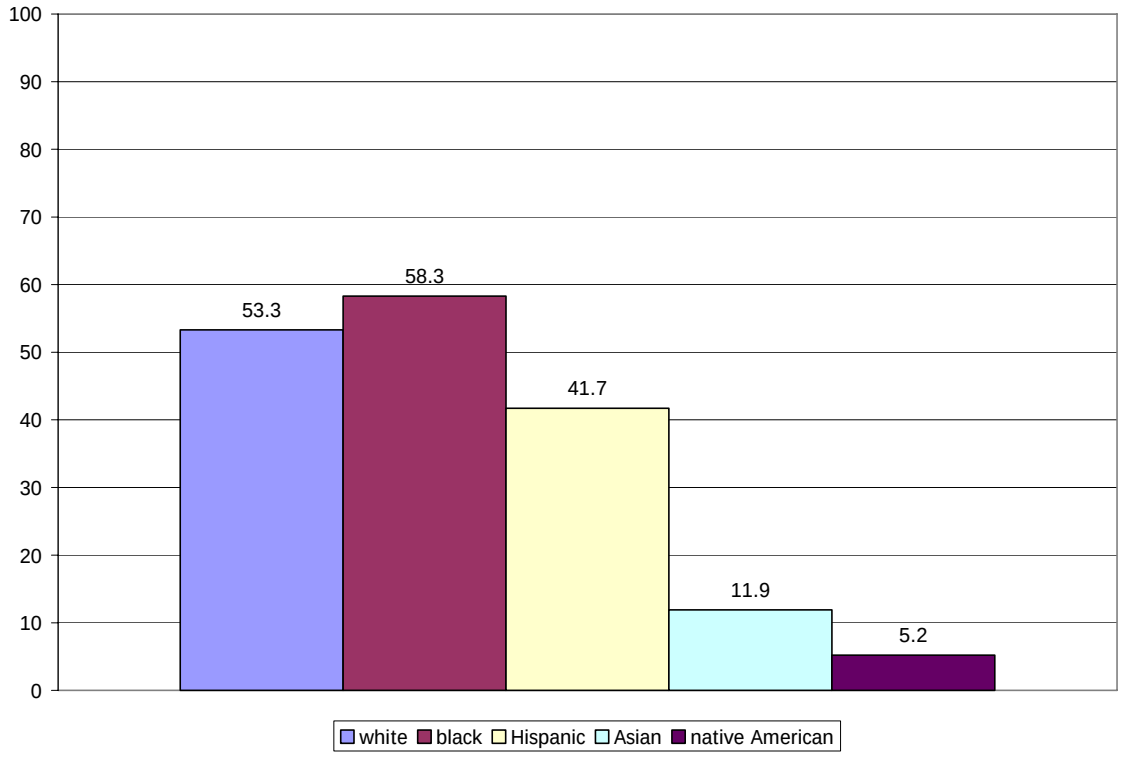
| Outcome Measure | Percent of 2001-2005 publications |
|---|---|
| Utilization of dental care | 30.6 |
| DMF, DMF variant, or ICDAS | 14.5 |
| Access to care | 14.0 |
| Cases (as in case-control study, e.g.) | 10.9 |
| Self-reported oral health | 10.9 |
| Biomarkers (S. mutans, e.g.) | 6.8 |
| Pocket depth or attachment loss | 6.6 |
| Satisfaction or quality of care | 4.3 |
| Costs | 3.0 |
| Mortality | 2.1 |
| Others | 1.7 |

Note: percentages may add to more than 100 because the categories are not exclusive.

In terms of populations, the oral health disparities literature emphasized race and ethnicity, as well as low income populations. Figure 3.11 shows the representation of various racial and ethnic groups in the oral health disparities literature. White, black, and Hispanic populations were frequently included in

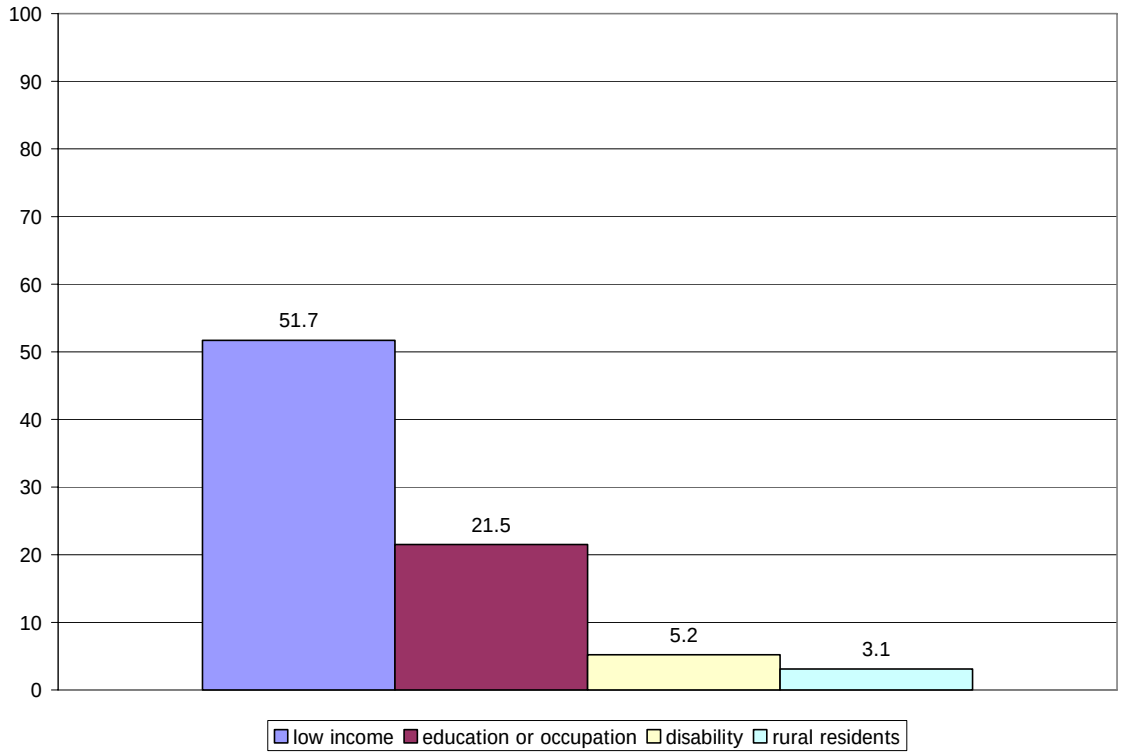
this research, while few publications included Asians or Native Americans. Low income was the most common measure associated with underserved populations. Over half of the health disparities literature identified low income populations. Education or occupation was also commonly used. However, very few studies were directed at rural residents or persons with disabilities. (See Figure 3.12.)

Figure 3.11: Percent Articles with Representation of Racial and Ethnic Groups in the Oral Health Disparities Literature, 2001-2005




Note: percentages may add to more than 100 because the categories are not exclusive.

Figure 3.12: Percent Articles with Representation of Underserved Groups in the Oral Health Disparities Literature, 2001-2005




Note: percentages may add to more than 100 because the categories are not exclusive.

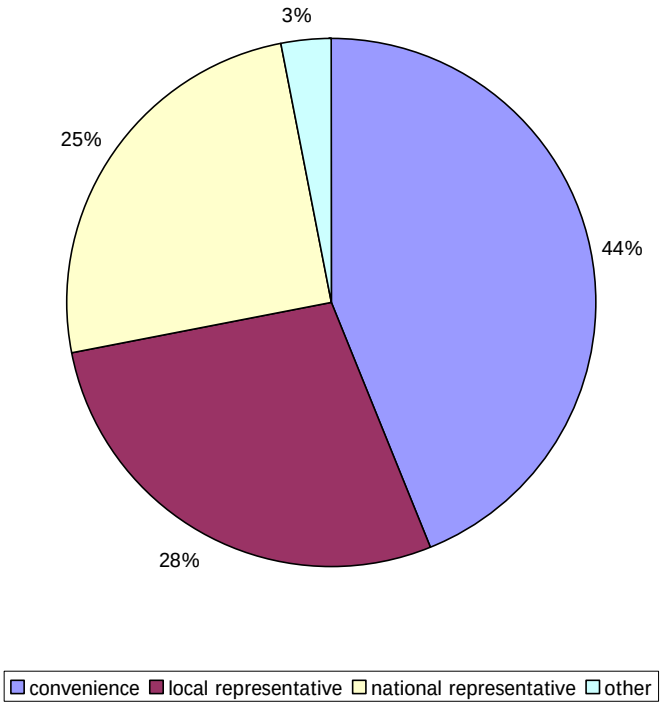
Researchers frequently made comparisons across the population groups identified in the analysis. For example, some researchers compared oral health status or utilization among blacks to oral health status or utilization among whites.[8] Over half--57 percent of the publications involved these types of comparisons, while the remaining 43 percent focused on oral health within a single, targeted disparity group.

Although comparisons across broad population groups were common, comparisons of population subgroups were rare. Most of this research treated African Americans, Hispanic Americans, and Native Americans as homogeneous groups. For black, Native American, Native Alaskan, Hispanic, and Asian populations, less than 4 percent of articles distinguished between any subgroups. For disability populations, only 2 publications in total made subgroup distinctions.

[8] For example, see L.N. Borrell et al, "Is There Homogeneity in Periodontal Health Between African Americans and Mexican Americans?", Ethnicity and Disease, 2002, 12, 97-110.

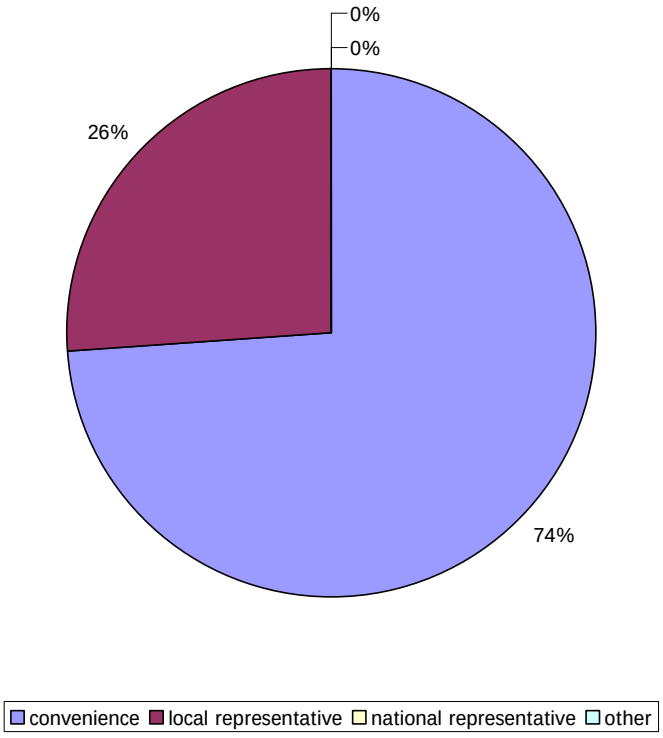
The subject populations in oral health disparities research were drawn and identified using a variety of sampling techniques. As shown in Figure 3.13, the most common technique was the convenience sample. Slightly over one quarter of the articles included a sample that was in some way representative of a defined population (either a local geographic area or a specific subgroup, such as Medicaid recipients). Other publications drew from nationally representative samples such as the National Health and Nutrition Examination Survey (NHANES) and the National Health Interview Survey (NHIS).

Figure 3.13: Percent of Oral Health Disparities Research Literature, 2001-2005, by Sample Type




It should be noted that these overall figures masked significant differences across types of research. The representative samples--particularly the national ones, but also the local ones--were generally used for the epidemiological and health services research that made up the bulk of the literature. The very few intervention studies in this area have been conducted very largely with convenience samples. (See Figure 3.14.)

Table 3.14: Percent Intervention Research in Oral Health Disparities, 2001-2005, by Sample Type




## Preliminary Results of NIDCR Oral Health Disparities Centers--Publications

The Centers for Research to Reduce Oral Health Disparities were funded by NIDCR in late 2001. The five centers were each funded for a 7 year period. As of January 1, 2007, the centers had been in operation for a little over 5 years. At that time, 74 percent of center studies were still ongoing, including several large clinical studies and trials.

Although it is too soon at this point to fully assess the results of the centers, as of January 1, 2007 the five centers had published 44 research articles directly from the centers' work. Of these, 36 (82 percent) represented original research. The centers' early publications reflected much of the same areas as the overall research literature. However, the center publications were more often concerned with risk factors (42 percent, compared with 18 percent of the overall literature) and interventions (11 percent, compared with 6 percent of the overall literature) whereas publications by others were concerned primarily with disease prevalence.

## Chapter Four: Identifying and Filling the Gaps in Oral Health Disparities Research

In our 2003 and 2006 case study visits, we asked key researchers at the Centers for Research to Reduce Oral Health Disparities what they felt were the most important things that needed to be done to address health disparities. Their answers, combined with the information from the grant portfolio and literature analysis, identified several key gaps and crucial needs in disparities research.

### Identifying the Gaps

#### Intervention Research

When asked what should be done to address oral health disparities, center researchers identified intervention research as a critical need. Table 4.1 shows the scientists' vision of the disparities problem in 2003 and 2006. In both years, center investigators identified intervention research as a major need, but by 2006 additional intervention research had become the most common recommendation. In 2003, the type of research identified most often by center investigators was research to describe and document disparities--one of the most common types of research in the literature. By 2006, dramatically fewer investigators identified this area of research. The investigators increasingly focused on intervention research--one of the least common areas in the literature and an area with relatively few NIH supported research grants.

Table 4.1: Areas of Research Advocated by Center Investigators, 2006 and 2003

| Rank in 2006 | Description of Response | Percent of respondents, 2006 | Percent of respondents, 2003 |
|---|---|---|---|
| 1. | Intervention research | 58 | 26 |
| 2. | Behavioral research | 32 | 15 |
| 3. | Caries research | 28 | 9 |
| 4. | Prevention research | 27 | 8 |
| 5. | Research to understand causes and risk factors | 25 | 28 |
| 6. | Community based research | 17 | 22 |
| 7. | Oral cancer | 16 | 2 |
| 8. | Research to describe and document disparities | 12 | 41 |
| 9. | Multidisciplinary research | 11 | 6 |
| 10. | Policy research | 10 | 6 |

Note: percentages will add up to more than 100 because many participants gave multiple responses.

The center researchers' focus on intervention research was consistent with the composition of the centers' research projects. As Table 4.2 shows, the research projects that compose the centers are equally distributed among intervention and epidemiological areas, with a number of projects encompassing multiple purposes.

Table 4.2: Current Center Projects, by Area of Research Advocated by Center Participants

| Rank in 2006 | Description of Response | Percent of center projects |
|---|---|---|
| 1. | Intervention research | 41 |
| 2. | Behavioral research | 11 |
| 3. | Caries research | 59 |
| 4. | Prevention research | 41 |
| 5. | Research to understand causes and risk factors | 41 |
| 6. | Community based research | 48 |
| 7. | Oral cancer | 11 |
| 8. | Research to describe and document disparities | 41 |
| 9. | Multidisciplinary research | 15 |
| 10. | Policy research | 7 |

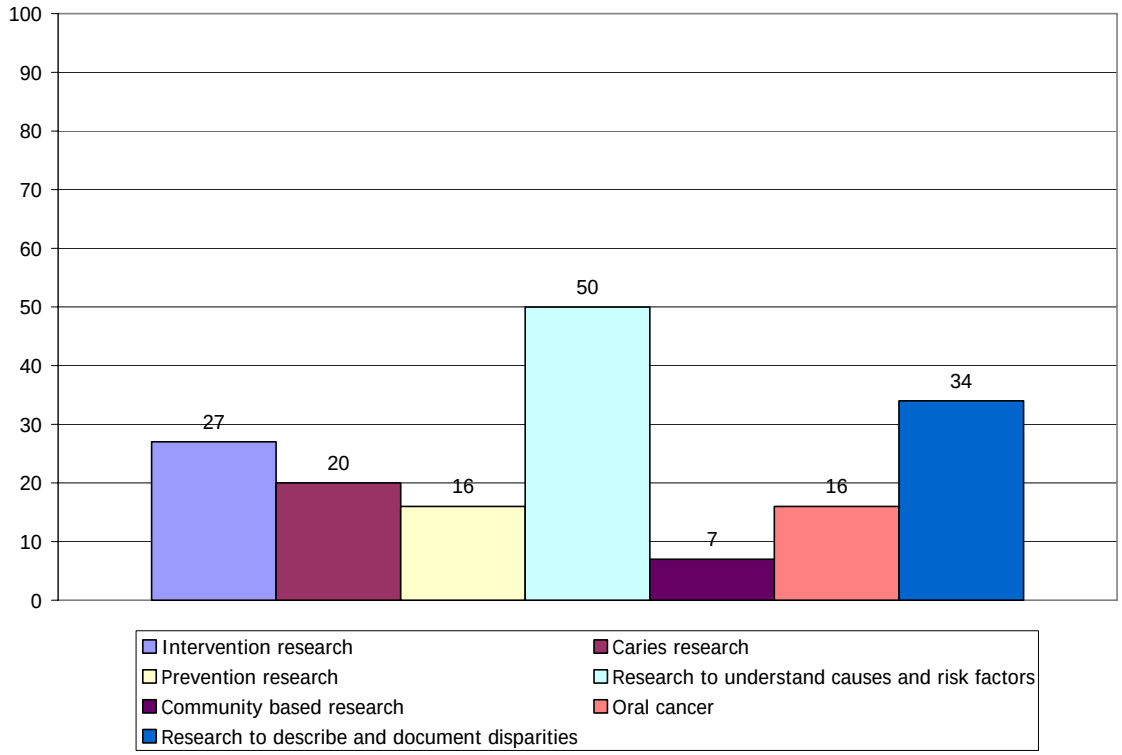
Note: percentages will add up to more than 100 because many projects fall in multiple categories.

The responses were generally consistent across researchers. There were only a few differences in staff responses across the disparity centers, and these appeared to be generally consistent with the differences in center activities. For example, investigators from centers with more intensive community involvement were more likely to give responses related to community based research. Responses from researchers were generally consistent within each center, regardless of the individual's role within the center.

We reviewed a number of NIDCR documents relating to health disparities to compare the researchers' vision of the problem with the vision expressed officially by NIDCR. With the exception of dental fear, every area of concern identified by the researchers was addressed by NIDCR's health disparities plan and/or by research solicitations related to health disparities.

The center investigators' responses, however, were less consistent with the areas of research they have pursued in their post-center grant applications. The center researchers have submitted some grant applications dealing with interventions, but they have submitted more in areas they identified as lower priorities. Since the centers were established, half of the grant applications submitted by center researchers in the disparities area were designed to understand causes and risk factors. Furthermore, over a third of the disparities applications submitted by these researchers related to documenting or describing oral health disparities. (see Figure 4.3.)

Figure 4.3: Areas of Research Advocated by Center Participants, by Percent of Subsequent Grant Applications

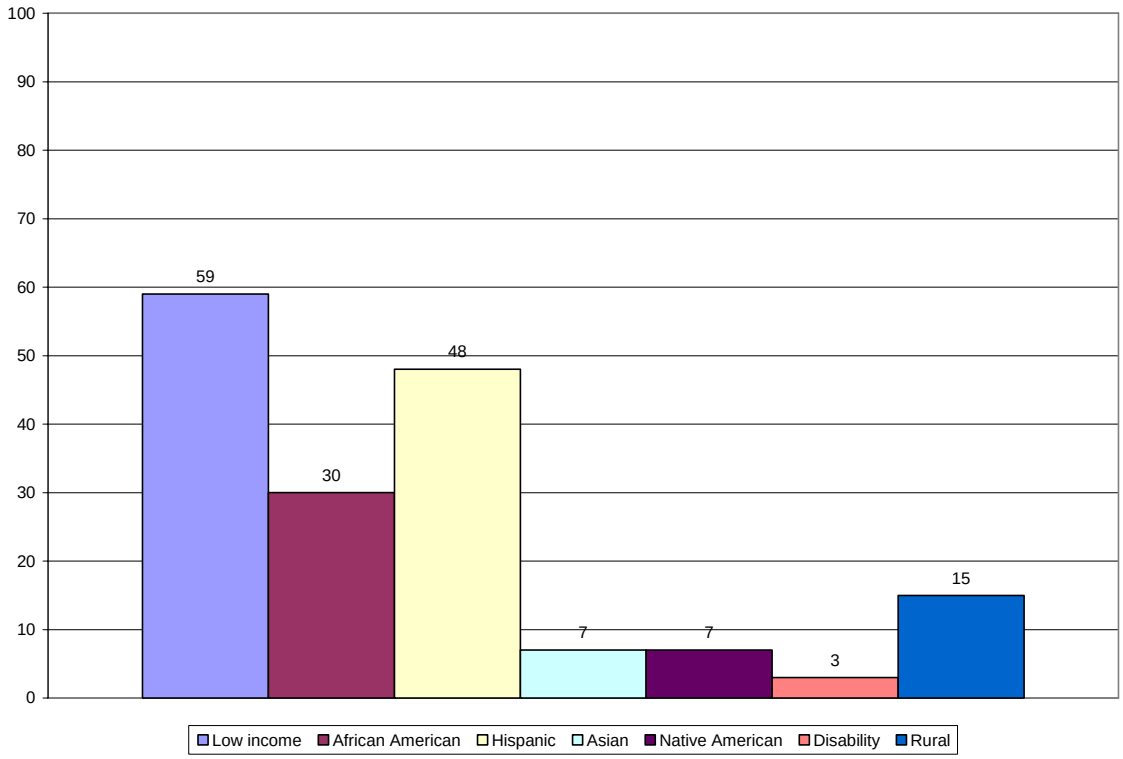



Note: percentages may add to more than 100 because the categories are not exclusive.

## Expanding the Reach of the Research Literature to Other Population Groups and Subgroups

Consistent with the overall literature on oral health disparities, the centers' projects focused largely on racial and ethnic minorities and low-income families. The only significant difference came in the higher percentage of center projects that address disparities impacting rural residents. (See Figure 4.4).

Figure 4.4: Percent of Center Major Projects by Subject Population




Note: percentages may add to more than 100 because the categories are not exclusive.

The centers' research projects addressed subpopulations to a somewhat greater extent than the overall literature. However, most of the centers' research projects did not distinguish among subgroups.

### Sampling Strategies

Like the overall oral health disparities literature, the centers' research projects relied largely on convenience samples. Only one of the centers attempted to draw a representative sample from a defined group, although one project in another center uses a representative sample from a larger study. Consequently, the results from many of these projects can not be generalized to a larger disparity population.

## Developing Additional Capacity to Meet Research Needs

To leading scientists in the field, the presence of significant research gaps is unsurprising because of the small number of researchers working in this area. With only about 100 original research articles published annually, the field of oral

health disparities research is limited in reach and size. In addition, few researchers concentrate their time and effort on disparities issues. In light of the small size of the field, it will be necessary to expand research efforts related to oral health disparities in order to address these gaps. This might include intensifying the focus of those already in the field, attracting experienced researchers from other fields, or training young researchers to work on disparities issues.

Furthermore, center participants told us that a vital component needed to fill these research gaps is the strengthening of relationships in the community. They strongly emphasized the need for community based research. Center investigators told us that researchers will not be able to access the desired populations, expand their sampling strategies, or develop effective interventions without substantive community participation.

## Chapter Five: Centers' Experience Suggests that Community Involvement is Necessary, but Also Challenging

The NIDCR Centers for Research to Reduce Oral Health Disparities were intended to develop further capacity for conducting community-based research related to oral health disparities. This was an especially important aspect of the centers because the rest of NIDCR's health disparities research portfolio emphasized smaller grants, where the resources for community involvement were limited. To explore how this capacity was being developed, we analyzed the centers' projects and activities related to the community. At both the baseline (2003) and follow-on (2006) case study visits, we asked the center participants several questions about their relationships with the community. We also visited community organizations that were working with the centers, and we asked the community partners similar questions.

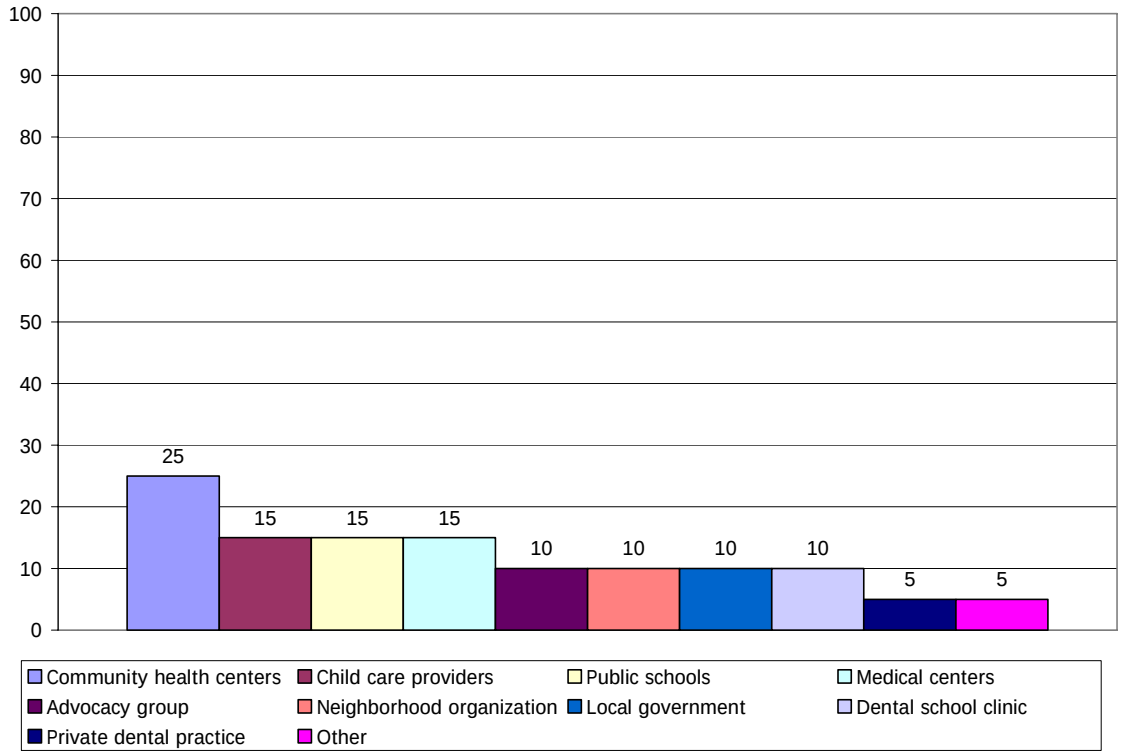
### Centers Varied in their Degree of Community Involvement

There was substantial variation both within and across centers in the level of community involvement in research projects. In one center, the community was not substantially involved in any of the center's research or other activities. In other centers, community involvement was a key feature in all the major research projects. Within some of the centers there was also variation, where some projects had a key community component and others none at all. In total, however, 78 percent of the centers' major research projects involved the community to a greater or lesser extent.

The roles of the community partners also varied considerably from project to project and from center to center. Some community partners were involved only in assisting center investigators to recruit research subjects. Other organizations provided some consultation to center researchers. Still others took on more of a partnership role in the design and/or execution of the research—reviewing study instruments, suggesting alterations to the design, and consulting on the interpretation of the results.

Figure 5.1 shows the types of community organizations most often involved in center projects. The four most common organization types were community health centers, medical centers, child care providers, and public schools—organizations most often associated with subject recruitment.

Figure 5.1: Percent of Major Center Projects by Type of Community Organization, 2006




Note: percentages may add to more than 100 because the categories are not exclusive.

Of all the disparities center projects that were involved with the community, 75 percent were involved with only one type of community organization, and 70 percent had only a single community partner.

## Centers Reported Benefits from Community Involvement

In 2006, we asked the center researchers about the benefits of community involvement for research. As shown in Table 5.2, two key factors were each mentioned by a majority of respondents. Center researchers cited the community involvement as important in helping to recruit and retain research subjects. The number of researchers who stated that involving community organizations helped improve recruitment and retention increased between 2003 and 2006. Although researchers generally agreed that recruiting and retaining research subjects in disparity populations can be challenging, they also expressed confidence that with the help the community, they were able to do so. For example, one center developed a close relationship with a community health center where they were conducting a study. The community organization provided personal support and assistance for study participants, helping the

researchers retain a high proportion of subjects despite the frequent mobility of the population in the area.

In 2006, an equal number of center researchers stressed the importance of community relationships for improving the quality of the research by allowing investigators to develop an appreciation of community challenges and perspectives. For example, one center project had planned to use peer interviewers to administer a study instrument. Community partners persuaded the center researchers to change the study design by pointing out the high probability of prior relationships between the interviewers and the subjects. Similarly, for another center, community feedback led to substantial changes in the health promotion materials designed to be part of the research intervention.

Table 5.2: Benefits for Research from Working with the Community

| Response | Percent of center participants, 2006 |
|---|---|
| Recruiting and retaining research subjects | 59 |
| Appreciation of community challenges and perspectives | 59 |
| Spreading the word about center activities and findings | 10 |
| Improve center credibility in community | 6 |

Note: percentages may add to more than 100 because the categories are not exclusive.

## Promoting Community Involvement Proved Challenging for the Centers

In both 2003 and 2006, community partners and researchers involved with the community strongly emphasized the need for relationships to be reciprocal—that is, researchers could not reasonably expect community participation unless they were able to deliver some tangible benefit to the community. Furthermore, researchers and community partners both stressed the need for these partnerships to be developed as longer-term commitments. There was a strong need to avoid "parachuting"—that is, researchers developing relationships with community partners and then pulling out as soon as the project is complete. Because developing community relationships takes time and effort, and because long-term commitments are required, researchers and partners agreed that these relationships should not be entered into lightly.

Some investigators expressed frustration because they felt they were unable to respond to the needs of the community as much as they would like. Research funding is just that—funding for research—and some ways of giving

back to the community may require additional resources. Both researchers and community partners recognized that community organizations were generally trying to address extensive needs with very limited time and resources.

Community partners also pointed out that they may have to devote scarce time and attention to learning various regulations and procedures involved in the research process—mastering a detailed research protocol or learning privacy regulations, for example. The stronger the community partner's role in the project, the more time and effort may be required. Often little or no compensation was provided for this effort, despite the ability to do so within regulations and despite the substantial benefit provided by the community to the project.

In 2006, we asked center participants who were involved with the community to describe the benefits the community received from interaction with the researchers. The responses are summarized in Table 5.3 below. The most common response was providing health education and/or health promotion efforts, either to the community organization staff or its clients. Some researchers involved with the centers developed service arrangements with community partners to provide additional dental care. The altruism of community partners was also stressed by both community partners and researchers. Nearly a third of respondents indicated that the community appreciated the opportunity to become involved in research simply because they believed the project itself was worthwhile.

Table 5.3: Participant Responses on Community Benefits from Research, 2006

| Response | Percent of center participants |
|---|---|
| Health education and/or health promotion | 40 |
| Direct health care services | 36 |
| Appreciate being involved in important research | 32 |
| Employment opportunities | 15 |
| Instruments for future community use | 13 |
| Assistance in pursuing additional funding | 11 |

Note: percentages may add to more than 100 because the categories are not exclusive.

The time and effort required on both sides of these partnerships was substantial, and pointed to the need for a robust organizational structure to support community relationships. Only one center had set up a community core; however, several used community liaisons to maintain the relationships between

the center and the community. Many center participants pointed out that cultural factors can prove very important in establishing and maintaining trust, and they relied on the community liaisons to "translate" between the groups and prevent misunderstandings. However, focusing the community liaison function on a single person—on either side—can also be risky. In more than one case, centers "lost" a carefully constructed relationship with a vital community partner when circumstances changed and a key person was not longer involved. Combined with the fact that many center projects were working with only one community partner, this points to a fragility of these important and necessary relationships.

The centers received very little support from their home institutions—the dental schools—for working with the community. Some centers were able to obtain the dental school's support for providing services, but others needed to set up volunteer clinics and other mechanisms to help the community. We interviewed the deans of each dental school where the centers were located, and only one was knowledgeable about the center's activities in the community.

## Chapter Six: Increasing Research Capacity in Oral Health Disparities

As we saw in our analysis of the overall literature in Chapter 3, the oral health disparities literature is relatively small, and there are a number of large research gaps. In order to address these issues it will be necessary to expand research capacity in the field of oral health disparities. Several potential strategies are available for strengthening the research infrastructure--(1) training young researchers in the arena of disparities research; (2) encouraging researchers who are currently working in the field to increase their focus on disparities issues; and (3) attracting experienced researchers from other fields to disparities research.

### Training Young Researchers in the Area of Oral Health Disparities

Center researchers expressed a strong desire to train young researchers in the area of oral health disparities. However, few young researchers were trained under mentors affiliated with the disparities centers in the 2001-2006 time period. As shown in Table 6.1, center participants suggested a number of strategies to attract new trainees to the field. Providing additional funding for training was the most frequent response, but it was closely followed by increasing awareness of health disparities as an important public health issue. In addition, senior investigators expressed concern about the potential for these young trainees, once they finish their training period, to obtain the research funding they will need to establish independent careers. They stated that if the research community does not see health disparities as a well-supported field, young people may want to start their careers in another area where they feel they can become independent sooner. Finally, center researchers pointed to the importance of mentoring opportunities for trainees. Several investigators emphasized that with the limited number of researchers working in the area, few mentors may be available to young trainees.

Table 6.1: Center Participants' Suggested Strategies for Attracting Trainees, 2006

| Response | Percent of center participants, 2006 |
|---|---|
| Provide additional funding for training | 35 |
| Increase awareness of health disparities | 30 |
| Provide additional funding for research | 26 |
| Provide mentoring opportunities | 26 |
| Advertise opportunities in the field more widely | 19 |
| Improve the dental school curriculum | 18 |

Note: percentages may add to more than 100 because the categories are not exclusive.

Although some center participants advocated additional funding for training, the majority of the centers had not fully leveraged the sources of training funding available to them. For example, only one center included an individual trainee who was supported under a NIH fellowship grant (F grant), and only 2 centers included individuals who were supported under a NIH career development award (K grant). Although T32 programs were in place at all 5 dental schools where the centers were located, only 2 centers included trainees supported under the T32 grant. Three centers received diversity supplements from NIDCR. In total, one center was able to leverage training funds from 5 of the 6 possible sources. However, two of the remaining centers used only one source of training support. In both cases this came relatively late in the life of the center, so for most of the grant period these two centers were unable to leverage any additional training support.

## Increasing Current Researchers' Focus on Disparities Issues

As we saw in Chapter 3, at least 90 percent of the investigators who published original research in the area of oral health disparities could be classified as "dabblers"--that is, although they published an occasional article about oral health disparities, the primary focus of their research was elsewhere. At baseline, this was also true of the investigators that made up the Centers for Research to Reduce Oral Health Disparities.

Subsequent publications and grant applications show some growing emphasis on disparities, although not a dramatic increase. Additional disparities articles are now emerging from this group of researchers, both from their center projects and from other research endeavors. Over the 2003-2006 period, 22 percent of the papers published by the center researchers were in the area of oral health disparities. Of the researchers that had been involved with the center for a minimum of 3 years, 75 percent had published at least 15 percent of their papers in disparities research.

A number of factors were associated with whether a researcher or group of researchers increased their focus on disparities issues. For instance, the percent effort devoted to the disparities center was associated with an increasing emphasis on disparities in publications and grant applications. Some of these articles and grant proposals could be directly tied to the center's projects and others were direct spin-offs. However, some researchers developed new disparities research projects outside of the focus of the center. One center researcher attributed some of her additional disparities efforts to the opportunities for collaboration that came about as other researchers found out about the center's activities. The number of roles that researchers played in the center was also associated with new publications related to disparities.

Researchers who worked on more than one center project, for example, were more likely to submit additional disparities-related grant applications. However, it proved difficult to separate the effects of increased percent effort from those associated with multiple roles, as these variables were associated with each other. Finally, the degree to which the center's components were interrelated was also associated with researchers' emphasis on disparities issues. These factors are discussed in more detail in Chapter 7.

## Attracting Experienced Researchers from Other Fields to Disparities Research

One potential strategy for increasing research capacity in oral health disparities could be to attract experienced researchers from other fields. We asked center participants what strategies they would suggest to attract such researchers. Their responses are summarized in Table 6.1 below. The most frequent strategies suggested were expanded funding opportunities, creating personal contacts, and creating a collaborative environment for research.

Table 6.1: Center Participants' Suggested Strategies for Attracting Experienced Researchers, 2006

| Response | Percent of Center Respondents, 2006 |
|---|---|
| Provide additional funding opportunities | 45 |
| Create personal contacts | 31 |
| Create a collaborative environment for research | 23 |
| Increase awareness of health disparities | 20 |
| Advertise research opportunities more widely | 10 |
| Draw on interests outside of oral health | 8 |

Note: percentages may add to more than 100 because the categories are not exclusive.

However, as of 2007 the centers had seen mixed results in attracting experienced investigators from other fields to oral health disparities research. The centers attracted 10 researchers outside of oral health during their first five years; however, 4 of those left the centers and the field during that time, and another 2 were approaching retirement. Of the remaining 4 researchers, 3 had been working with the centers for less than 2 years. While it is too soon to tell if the centers' efforts will ultimately be successful, the initial results suggest that the strategy of attracting experienced researchers may not be as fruitful as some in the centers had hoped.

A number of center respondents stated that it is important to increase awareness of oral health disparities in the broader research community. In the

initial RFA for the centers, each center was asked to develop "national networks" and to "serve as a national resource" to promote oral health disparities research. In both 2003 and 2006, some center participants expressed uncertainty as to how they were to go about this broad goal. We asked the center participants to describe their efforts to promote oral health disparities research and to serve as a national resource. Their responses are summarized in Table 6.2 below. The most common responses centered on supporting pilot projects, raising awareness (most often through the center's web site), and providing technical assistance.

Table 6.2: Research Promotion Activities, 2006 and 2003

| Response | Percent of Center Responses, 2006 | Percent of Center Responses, 2003 |
|---|---|---|
| Raise awareness (center web sites) | 27 | 14 |
| Pilot projects | 27 | 17 |
| Links to other centers | 27 | 6 |
| Technical assistance or consulting | 25 | 22 |
| Seminar series or conferences | 20 | 8 |
| Sharing instruments or measures | 15 | 7 |

Note: percentages may add to more than 100 because the categories are not exclusive.

In both 2003 and 2006, not every participant was able to respond to this question. Furthermore, with the exception of the center web sites, which were mentioned at 4 of the 5 centers, there was considerable variation in responses by center. This variation reflected the differences in these activities across centers.

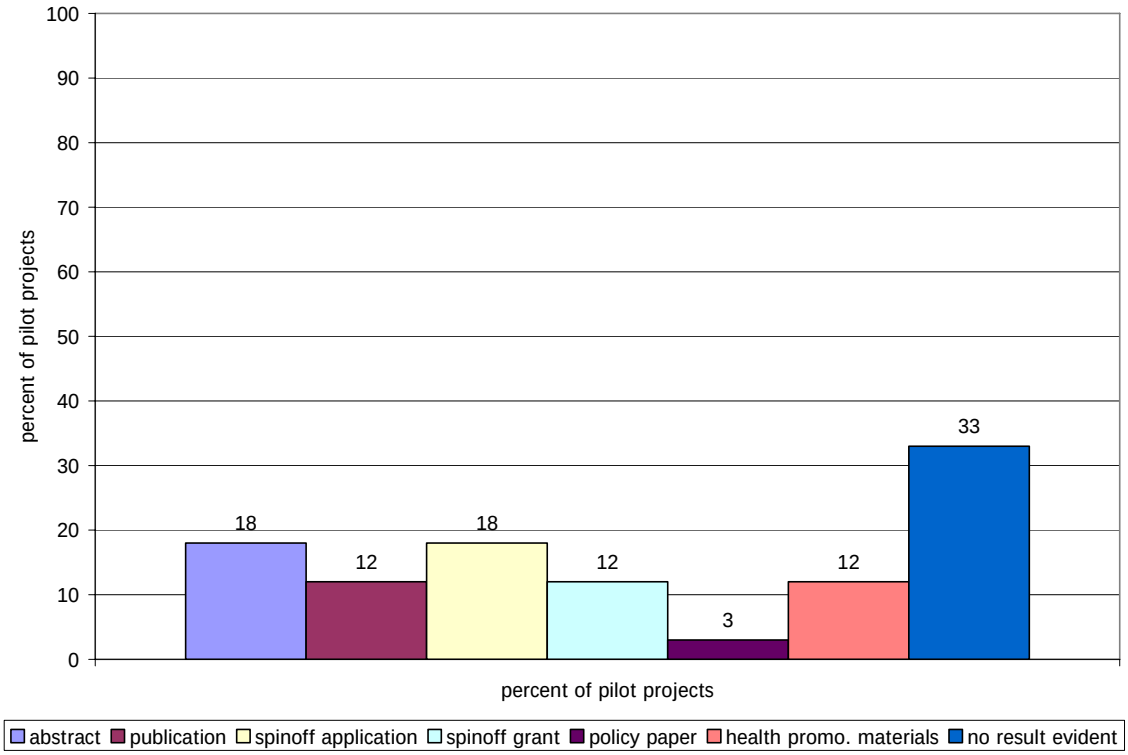
The center web sites were reviewed by the evaluation team to determine whether potential contacts could find the web site, whether informative content was provided, whether the site's information was up to date, and whether the site was navigable and accessible to persons with disabilities. The instrument for this assessment was developed by the evaluation team and reviewed by experts at NIDCR's Office of Communication and Health Education. The centers' web sites did not generally perform well under the evaluation criteria. On a scale of 0 to 100 on the evaluation instrument, the centers' scores ranged from 9 to 62 percent. Most sites provided very limited information, and this information was not updated. Three of the sites were very difficult to find even with the aid of a search engine. A more complete description of the results, including a copy of the study instrument, is provided in Appendix D.

The evaluation also directly addressed the impact of pilot projects. The centers were able to award small pilot projects to experienced researchers (not

student trainees) to test extensions of a larger project or to jump-start new disparities research that related to the center's theme and major projects. These pilot projects allotted small amounts of funding (usually $15,000) for one to two years. Some centers used pilots extensively. However, other centers found the restrictions on pilots (such as the need to fit the theme) restrictive, and they funded only a few pilot projects.

As seen in Figure 6.3, two-thirds of the pilot projects (67 percent) yielded some traceable, tangible outcome, whether that was a conference abstract, publication, or other product. A total of 3 funded grants, and 9 grant applications, could be traced to the center pilot projects.

Figure 6.3: Results of Center Pilot Projects




Note: percentages may add to more than 100 because the categories are not exclusive.

In addition to pilot projects, the centers were able to include "affiliated projects" in their activities. These "affiliated" projects were funded by sources other than the center, but included under the center's administrative umbrella. The PIs and teams in these affiliated projects could thus benefit from the center's resources and participate in center activities. Three of the five centers included affiliated projects. A list of these projects is provided in Appendix E.

As of 2007, the affiliated projects had little impact on the rest of the center. There was variation from center to center in how intensively the affiliated projects were connected with the center. In one center, the affiliated projects were not at all closely connected with the center--their investigators did not regularly attend center meetings and did not generally participate in other center activities. In the other two centers, the affiliated projects attended center meetings and benefited from the center's cores. However, even in these centers, the affiliated projects did not have traceable "spillover" effects into the rest of the center. Specifically, the affiliated projects did not spawn collaborations with center staff that resulted in new publications or grant applications.

In the 2006 interviews, a number of staff at different centers related that they were disappointed about the lack of interaction across the disparities centers. Only 2 original research publications and 2 grants involved investigators from more than one center, and these few involved collaborations that had been established prior to the centers. Center participants acknowledged a number of barriers to cross-center collaboration. These included feelings that centers are competing for research support; a lack of resources and incentives to support cooperative efforts; and uncertainties about the benefits of specific collaborations.

## Chapter Seven: Impact of Research Mechanism and Center Organization

At NIH, research can be supported using a number of funding mechanisms. The most common of these is the R01 mechanism, which is generally used for an individual research project lead by a single investigator. Centers, like the Centers for Research to Reduce Oral Health Disparities, are generally larger grants that encompass multiple research projects under a single administrative organization. The choice of mechanisms to support a particular line of research can be a difficult one. One of the objectives of this evaluation was to explore the implications of this choice by reviewing the impact of the research mechanism, and (within the centers) the center organization, for the end results of the research.

### Advantages and Disadvantages of Centers

We asked individuals who participated in the Centers for Research to Reduce Oral Health Disparities to describe for us the potential advantages and disadvantages of the center structure as compared with a group of individual, R01-type projects.[9] The advantages of a center as reported by the researchers are shown in Table 7.1. The results were fairly consistent across time. In both years, by far the most common response was that centers promote sharing and collaboration among researchers. Several project PIs, belonging to different centers, went so far as to tell us that if a center does not promote collaboration, there is no use in having a center. Over one-third of respondents also stated that centers are a superior mechanism for promoting multidisciplinary or interdisciplinary research. Individuals who worked with the community often related that centers were a better mechanism for getting the community involved in research. One community liaison told us that it might be difficult for an individual investigator to establish community relationships on his or her own, but that having a center organization made these relationships easier and more credible. Economies of scale were also cited as an advantage of a center structure. This response was more common in centers with more active cores that served a greater number of projects. With this exception, responses were generally consistent across centers and among individuals with different roles in the centers.

[9] In 2003, for comparison purposes we also asked the same questions of a small number of R01 researchers who were not involved in the centers. The responses were very consistent across R01 and center researchers. For responses reported previously, the denominator is all interviewees--for the responses in this report, the denominator is all the individuals who answered this particular question. (NIDCR, "Evaluation of NIDCR Oral Health Disparities Program: Baseline Evaluation Data", May 28, 2004.)

Table 7.1: Potential Advantages of a Center, 2006 and 2003

| Response | Percent of Center Respondents, 2006 | Percent of Center Respondents, 2003 |
|---|---|---|
| Promote sharing and collaboration | 72 | 79 |
| Promote multidisciplinary research | 34 | 22 |
| Better mechanism for involving community in research | 25 | 20 |
| Economies of scale and shared resources | 24 | 25 |
| Helps attract good researchers | 13 | 3 |
| Better for mentoring young researchers | 10 | 16 |
| Helps coordinate research towards an overall goal | 9 | 9 |
| Gives the institution status | 9 | 6 |
| Better mechanism to address complex questions | 7 | 13 |
| More financial flexibility; ability to re-allocate resources | 7 | 6 |

Note: percentages may add to more than 100 because the categories are not exclusive.

Many fewer responses were provided for the potential disadvantages of a center -- unsurprisingly, as the researchers we interviewed had chosen to become affiliated with a center. The perceived disadvantages of a center are summarized in Table 7.2. The most common responses related to administration and logistics, which were thought to be more difficult and time-consuming. Once again, the responses were generally consistent across centers and among people with different roles.

Table 7.2: Potential Disadvantages of a Center Structure, 2006 and 2003

| Response | Percent of Center Respondents, 2006 | Percent of Center Respondents, 2003 |
|---|---|---|
| Logistics are more difficult (budgeting, administration, coordination) | 35 | 24 |
| Less funding is available for a center subproject than a comparable R01 | 30 | 6 |
| Individual investigators may have less flexibility and/or less control over the research | 28 | 22 |
| Centers require a strong administrator or manager | 16 | 29 |
| For an investigator, being PI of a center project is less prestigious than an R01 | 11 | 4 |
| Centers may include some weaker projects | 8 | 1 |
| Centers require or involve more bureaucracy and NIH oversight | 8 | 16 |

Note: percentages may add to more than 100 because the categories are not exclusive.

## Elements that May Contribute to Center "Synergy"

Many of the advantages cited by center researchers above have to do with a concept known as "synergy". Synergy can be defined as the sharing or ideas, perspectives and resources among researchers and their studies to promote quality and efficiency in research. Ideally, a center with a high degree of synergy would be more productive than the same researchers would be if they worked separately on individual projects. For example, sharing and collaboration on projects can result in higher quality research if each investigator brings their own perspective and skills to a project. Similarly, some research can benefit from multidisciplinary collaboration, as different researchers bring the tools and background of their particular discipline to the group. Economies of scale, as can be gained from sharing core resources across more than one project, may result in efficiencies in conducting multiple studies.

In addition to increased research productivity, synergy can promote other positive outcomes. For example, a center with increased synergy might develop new directions and dimensions that takes the research in unanticipated, creative

paths. Synergy may enable researchers to wholly or partially combine research projects, or to generate a higher rate of interdisciplinary spin-off projects. Collaborations spawned by a synergistic environment may continue well beyond the life of a grant, and may also make researchers more receptive to new collaborations in the future. However, several researchers pointed out to us that if some type of synergy is not realized, many of the potential advantages of a center will not materialize. In this case, they cautioned, the disadvantages of a center may outweigh the advantages.

Through discussions with researchers and reviewing the evaluation research literature, we developed several hypotheses describing elements that may contribute to the "synergy" realized in a center. These included:

- *Stability and continuity* in the center staff and management;
- Degree of *investment* of center investigators in the work of the center;
- *Interdisciplinary* backgrounds of center researchers;
- The *organizational structure* of a center; and
- The *processes* used in a center for coordination and sharing of information.

Stability and continuity can by hypothesized to lead to synergy by giving researchers time to develop strong collaborations with each other and to learn from each other. Conversely, if new researchers are continually coming and going at a rapid pace, there is apt to be a "learning curve" that can negatively affect research production. Stability and continuity can also serve, as it does in the organizational and management literature, as a proxy measure related to staff morale and satisfaction. For the oral health disparities centers, we measured stability and continuity by assessing a variety of measures. These included, among others, the center's overall turnover rate, the turnover rate for key personnel (center director, project PIs, and core PIs), and the percentage of original staff still with the center in 2006.

If center staff are invested in the center's activities to a greater degree, they are putting in more time, effort, and resources into the work of the center. Organizational theory suggests that individuals who are highly invested in the mission of an organization often play multiple roles and work with many others to further the mission. These factors may lead to a greater degree of synergy and collaborative effort. For the oral health disparities centers, we measured investment using a number of different metrics. For example, we reviewed the percent effort of key personnel, the percent of key personnel with more than 2 roles in the center (for example, a project PI who served as an investigator on another project or core), the percent of non-research positions in a center, and the percent of center funding that went to people with relatively little percent effort.

A range of multidisciplinary backgrounds has been hypothesized to lead to synergy by providing a wide range of different skills and perspectives to a center. However, the degree to which a collaborative is multidisciplinary has proved challenging to measure and assess. We reviewed the distribution of key personnel by clinical background and by degree background.

Several researchers identified organizational features of their center that they believed promoted synergy and collaboration. For example, some centers were constructed as collections of largely independent projects, with little overlap among personnel on the different project teams. In other centers, the same researchers worked across multiple projects. Projects may be related in other ways than through their staff. For example, in some centers multiple projects share a targeted population or even a subject population. In others, the projects may share outcome measures, or may target a given disease or condition. We analyzed each of the centers in terms of the specific ways the projects related to or interacted with each other. We also developed a composite measure, where we computed the percent of the possible relationships between units (projects and cores) in a center that were actually realized.

The processes a center uses to communicate and coordinate among researchers may also have an impact on synergy and productivity. For example, other things equal, regular meetings and seminars may help develop communication among members of a center. We compared the reported frequency of these types of communications across centers.

## Centers Varied in Elements Potentially Related to Synergy

The five centers varied considerably on some of the elements described above, and not at all on others. Even within elements, the degree of variation depended on which metric was chosen. Table 7.3 below shows a few of the key metrics for the elements described above, indicating whether there was significant variation across the 5 centers. For stability/continuity, there was significant variation in several measures, with one center exhibiting high turnover and another being very stable. The investment variables exhibited the most variation across the centers, with both the higher and lower values significantly different from the middle range. The interdisciplinarity measures also varied. Some of the variables dealing with organizational structure differed across centers. Substantial and significant variation was present in the composite variable, the percent of percent of possible relationships among parts of the center that were realized.

Table 7.3: Indicators of Elements Potentially Related to Center Synergy, 2006

| Indicator | Significant Variation? | Low Value | High Value |
|---|---|---|---|
| *Stability/continuity* | | | |
| Overall turnover rate | √ | 22.0 | 37.4 |
| Turnover rate, key personnel | √ | 0.0 | 38.9 |
| Percent of original staff still with the center | √ | 35.0 | 70.6 |
| *Investment* | | | |
| Percent of positions in center that are consultants, administrative, or other non-research | √ | 14.1 | 39.2 |
| Percent of staff with more than 1 role in the center (for example, project PI, investigator, core PI, center PI) | | 11.4 | 25.4 |
| Percent of key personnel (center PI, project PI, core PI) with more than 2 roles in center | √ | 14.3 | 53.4 |
| Percent of total funding for personnel that went to people with less than 20 percent effort in the center | √ | 6.5 | 28.2 |
| *Interdisciplinarity* | | | |
| Percent with modal area background among physical sciences, dentistry, other biomedical sciences, social sciences, and other | √ | 22.2 | 80.0 |
| *Organizational Structure* | | | |
| Percent of possible relationships among units that were actually realized | √ | 16.0 | 66.7 |
| Percent of projects that share at least one investigator with other center projects | | 50.0 | 100.0 |
| Percent of projects that share at least two investigators with other center projects | √ | 0.0 | 57.1 |
| *Process* | | | |
| Frequency of reported meetings (per year) | | 12 | 12 |

## Preliminary Analysis Suggests Investment, Organizational Structure Potentially Associated with Spin-off Applications

In 2007, the centers are still in their initial funding period, many center projects are ongoing, and the publications from center research projects are emerging. Therefore, it is not yet possible to firmly associate elements related to synergy with the productivity of the centers. However, the first sign of future productivity appears in the form of spin-off grant applications from the center projects. These applications can serve as a "leading indicator" of research productivity. With that in mind, we used a simple limited dependent variable

model to test the potential relationship between the indicators above and the number of grant applications submitted that could be directly related as a "spin-off" to one or more center projects. Because multicollinearity made this very difficult, we selected only one indicator from each group, and we chose the one that exhibited the greatest variation across centers. The indicators used in the model are illustrated in green in Table 7.3.

Despite the clear and major limitations of this technique, the model suggested that some of the indicators were associated with a greater number of spin-off applications. We found that the indicators associated with investment and organizational structure were associated with a higher number of spin-off grants. The other metrics were not related to productivity. However, the limited number of observations and analytical challenges presented by the estimation technique make conclusions at best tentative.

## Chapter Eight: Conclusion

The evaluation of NIDCR's portfolio in oral health disparities research identified a number of achievements. The funding of the oral health disparities centers generated a number of spin-off grant applications and research projects. Additional researchers from both inside and outside the field of oral health have now become involved in oral health disparities research. However, the evaluation also revealed several challenges that go beyond the scope of a single funding agency, university, or research center. Each of these challenges related to developing increased capacity for oral health disparities research—increasing the number of researchers, broadening the scope of the evidence-base in health disparities, and generating additional community-based research.

The evaluation results clearly documented just how small the field of oral health disparities research is. Only slightly more than 100 original research articles were published per year, despite the extensive need for scientific research on disparities in caries, periodontal diseases, oral and pharyngeal cancers, and other oral and dental conditions. Furthermore, 90 percent of the authors who published articles on oral health disparities were researchers who concentrated their efforts in other fields. The experience of the disparities centers suggested that attracting experienced researchers from other areas, although potentially helpful, was by no means sufficient to fill the need for increased capacity in disparities research. Furthermore, the early experience of the disparities centers also suggested that individual scientists continued to work in the disparities area only after they had initially made a significant investment of time and effort in projects associated with the center. In summary, the results of the evaluation indicated that there was a great need for more researchers in the area. However, the evaluation results also suggested that individual scientists who make relatively small time commitments to disparities research are unlikely to continue their interest in the longer term.

The evaluation demonstrated that the field of oral health disparities research was narrowly focused, as well as small. The findings showed that the great majority of the publications in oral health disparities were concerned with health services research and epidemiology. Investigators associated with the disparities centers identified intervention research as a major gap in the literature. As they gained more experience with the oral health disparities research center, researchers increasingly called for more intervention research. However, scientists were not yet fully positioned to fill this gap—spin-off grants from the centers continued to focus in the areas of epidemiology and access to care. The evaluation results suggested that additional efforts to promote intervention research may be needed.

Finally, the evaluation of the disparities centers were also highly informative about the role of community-based research in the field of oral health disparities. The investigators identified two key benefits of a community-based approach to disparities research. First, researchers recognized that a community-based approach is often the best way to reach disparities populations and encourage them to participate in oral health research. Second—and equally important—center researchers stressed the importance of community relationships for improving the quality of the research by allowing the investigators to develop an appreciation of community challenges and perspectives. In many of the centers, scientists pointed to specific examples of how understanding the community context led to key changes in research design and implementation that resulted in a better study.

This recognition of the importance of community participation was accompanied by acknowledgement of the challenges researchers and research centers face in trying to implement a community-based approach. Scientists had to strike a difficult balance between meeting the needs of the community and being able to implement the research project effectively. Researchers often felt that they were unable to provide the community with sufficient tangible benefits from the project, especially when community partners took an active role in the project that required their scarce time, attention, and resources. In addition, center researchers indicated that it was sometimes difficult to sustain a long-term commitment to the community. The evaluation results suggested that creative solutions to these challenges were needed. Researchers and community participants suggested that these solutions might someday include more robust organizational structures, new partnerships, and increased support from academic institutions.

## Appendix A

### Community Organizations Included in Disparities Centers Case Studies, 2003 and/or 2006

Boston Public Health Commission, Boston
Whittier Street Health Center, Boston
Voices of Detroit
Eastside Neighborhood Service Organization, Detroit
Detroit Dental Health Project, Community Advisory Board
San Francisco Department of Public Health
Chinatown Health Center, San Francisco
San Francisco General Hospital Community Clinic, San Francisco
San Ysidro Health Center, San Ysidro
Yakima Valley Farmworkers' Health Center, Yakima
Heritage College, Toppenish, Washington
Centralia College, Centralia, Washington
Valley View Community Health Center, Centralia, Washington
Odessa Brown Community Health Center, Seattle
University of Puerto Rico, Community Advisory Board
Cantera Community Center, Puerto Rico